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‘Am I really gonna go sixty years without getting cancer again?’ Uncertainty and liminality in young women’s accounts of living with a history of breast cancer.

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*'Am I really gonna go sixty years without getting cancer again?'* Uncertainty and liminality in young women's accounts of living with a history of breast cancer.

## **Abstract**

Although much research has examined the experience of breast cancer, the distinctive perspectives and lives of young women have been relatively neglected. Women diagnosed with breast cancer under the age of 45, and who had completed their initial treatment, were interviewed, and social constructionist grounded theory methods were used to analyse the data. The end of initial treatment was accompanied by a sense of unease and uncertainty in relation to recurrence and survival, and also fertility and menopausal status. The young women's perceptions about the future were altered, and their fears about recurrence were magnified by the possibility of many decades ahead during which breast cancer could recur. The implications for the young women's life course, in terms of whether they would be able to have children, would not become clear for several years after initial treatment. This resulted in a liminal state, in which young women found themselves neither cancer-free nor cancer patients, neither pre- nor post-menopausal, neither definitively fertile nor infertile. This liminal state had a profound impact on young women's identities and sense of agency. This extends previous understanding of life after cancer, exploring the age-related dimensions of liminality.

## **Introduction**

The experience of receiving cancer treatment, and subsequently living long-term with a history of cancer, is becoming more and more common. Breast cancer is the most common cancer in the UK, and the survival rate is one of the highest, with around 8 in 10 women living beyond ten years. This means that there exists a large population of women living with a history of breast cancer. Interest in women's experiences of breast cancer has grown since the 1980s, alongside the increase in research about the experience of illness in the field of the sociology of health and illness [1]. Yet, the

experience of being a young woman living with a history of breast cancer remains relatively underexplored, particularly in the UK. Around 80% of breast cancers in the UK are diagnosed in women over 50 [2], but the numbers of younger women diagnosed each year have been steadily increasing in the UK, and in Europe as a whole [3, 4], and it is the most commonly diagnosed form of cancer in women aged 18-39 in the UK. Thomas-MacLean [5] argued that “the ramifications of breast cancer and its treatments affect all spheres of life, including appearance, family relationships, moral dilemmas, and interactions with medical professionals” (p.638), and the impact continues long after the end of treatment. A recent report from Macmillan Cancer Support [6] highlighted the long-term consequences of cancer and argued that “we have to recognise that ‘not dying’ [from cancer] is not the same as ‘being well’”.

This study aimed to explore the experiences and perceptions of young women living with a history of breast cancer in the UK. This paper focuses on the impact of breast cancer on a young woman’s life course and identity. Specifically, it explores the effect of the uncertainty engendered by the diagnosis and treatment of breast cancer at a young age, and the evidence for resulting liminality in the young women’s accounts.

### *Liminality*

The concept of liminality [7] emerged through the literature review as potentially relevant to understanding the experiences and perceptions of young women living with a history of breast cancer. Liminality as a concept first originated in anthropological studies of rites of passage [8, 9]. Such rites of passage were observed to begin with a severing of the connection with a previous social position, followed by an ambiguous stage, before the individual re-enters society with a new identity and occupies a different position in the social structure [10, 11]. The ‘liminal’ state is the middle stage, characterised by uncertainty and in which the person is situated “betwixt and between fixed social positions” [10].

Although the concept emerged from anthropological studies, it has been used in recent decades to describe the experience of living with a history of cancer. Little *et al.* [7] argued that a person who has had cancer enters into a state of liminality in which he or she is classified as neither ill nor well. Little *et al.*'s formulation differs from the earlier anthropological work because they did not conceptualise it as three separate stages, but as a process; "an enduring and variable state" [7]. Little *et al.*'s formulation echoes Sontag [12], who argued that people who have had cancer belong fully to neither the "kingdom of the well [or the] kingdom of the sick", as well as Frank's [13] description of the 'remission society'. There were three themes in the accounts of people with a history of colorectal cancer which Little *et al.* identified as constituting liminality: 'cancer patientness'; 'communicative alienation'; and 'boundedness' (p.1486). 'Cancer patientness' referred to the way that, regardless of length of time since treatment, respondents continued to speak from the position of a cancer patient and described the ways that everyday life was irreversibly changed, with cancer occupying their thoughts most days. Interviewees talked about a sense of alienation and separation they felt from those who had not had cancer, and the authors named this 'communicative alienation'. 'Boundedness' referred to the experience of feeling restricted in terms of time and space (such as staying in hospital during recovery from surgery), and the surrendering of social and working roles. Participants felt a sense of uncertainty about the future and limitations in the freedom to move through space, particularly because of the physical constraints which having a stoma bag entailed in terms of requiring access to bathrooms.

Drawing on Little *et al.* (1998), a small number of studies have used the concept of liminality in research about living with a history of breast cancer [14], prostate cancer [15, 16], and various types of cancer [17]. Hubbard and Forbat (2012) found that participants perceived cancer as a continuing threat regardless of the time since diagnosis or the presence of long-term physical effects of treatment, and also that cancer was referred to as an ongoing threat in terms of recurrence more amongst participants diagnosed under the age of 50, although they did not explore why this might have been. In Navon and Morag's [15] study, men reported that treatment left them feeling simultaneously 'better' and 'worse' because, while the symptoms of prostate cancer had been remedied, they

experienced other losses in terms of libido and impotence. Cayless *et al.* [16] expanded on this work, finding that the language used by the men in their study often suggested that they were caught between fear of recurrence and hope of change, illustrating liminality. The current study builds upon this literature, contributing the stories of young women with a history of breast cancer, and looking at the significance of age in the experience of liminality after cancer. Little *et al.*'s conception of liminality will be drawn on in exploring the young women's accounts.

### *Fertility*

An important aspect of living with a history of breast cancer as a young woman is the impact of treatment on fertility and menopausal status. Treatment for breast cancer, such as chemotherapy and Tamoxifen, can leave women with low or no ovarian function, and can cause young women to enter a premature menopause. Pregnancy rates for women beyond breast cancer have been shown to be 70% lower than in the general population [18]. Most women experience menopausal symptoms after breast cancer, and healthcare providers are often unable to tell women whether their menopause is temporary or permanent [19]. Concerns related to fertility have been found to be amongst the biggest concerns for young women living beyond breast cancer [20-22], and there have been recent calls for more research about the subjective experience of fertility and infertility after cancer [23, 24]. Researchers in this area have identified the significance of the uncertainty about fertility [23-25]. Findings from this body of research have echoed Little *et al.*'s themes of liminality. Halliday *et al.* [25] argued that women living with uncertainty about their fertility after treatment for haematological cancer felt profoundly different to and disconnected from their peers, reminiscent of Little *et al.*'s (1998) description of 'communicative alienation', as the women found it difficult to cope with the uncertainty of whether they would be able to go through the same experiences of having children as their friends and family. Halliday *et al.* also argued that the women in their study experienced a heightened awareness of the constraints of time, and a loss of the taken-for-granted assumptions that they would be able to have children, and that they had plenty of time in which to do so, similar to

Little *et al.*'s 'boundedness'. This was exacerbated by uncertainty such as about how long it would take to become pregnant, and whether they would need IVF treatment.

These findings indicate that the concept of liminality may have potential in understanding this experience and young women's perceptions of uncertain fertility after breast cancer. This study expands on this work, making the link between uncertain fertility and liminality after cancer. Previous research exploring breast cancer and liminality [14] has not considered the distinctive experiences of younger women such as those related to fertility, and how this might be understood in terms of liminality. While women living with a history of breast cancer may not currently have cancer, their history of cancer engenders uncertainty about the future in terms of recurrence, and also related to fertility. The concept of liminality facilitates insight into those whose experiences blur the boundaries between ill and healthy.

#### *The new normal*

There is a concept emerging in research and writing about cancer experience: that of the 'new normal' [14, 26-28]. In the oncologist Mukherjee's [26] book, a woman undergoing treatment states that, "for someone who is sick, this *is* their new normal" (p.449) [original emphasis]. She was referring to her everyday life which had become structured by treatment. Other research has described constructing a 'new normal' as a way of rebuilding one's identity and accepting that everyday life will never be quite the same [27, 28]. Trusson approached her recent research with the question 'what does the new normal look like for women living beyond breast cancer treatment?', thus assuming that there is a new normal after the end of treatment [14]. Indeed, Trusson's participants did not seem to be striving towards a return to normal, instead facing and sometimes embracing a new, altered identity. This study aimed to explore whether younger women living with a history of breast cancer were living with a new normal, given the uncertainty regarding fertility and menopausal status.

Existing research has looked at women's concerns about uncertain fertility after breast cancer for younger women, and in this paper I bring uncertainty and liminality together to show that uncertainty about fertility (and also menopause) shape a young woman's identity and sense of agency after breast cancer, as she finds herself between identities.

## **Methods**

This exploratory research was situated within the interpretive paradigm, a perspective which assumes that, in order to understand a social phenomenon, researchers must explore it from the perspectives of individuals experiencing it [29-32]. The aim was to understand the experience and meaning of being a young woman with a history of breast cancer from the perspectives of the young women themselves. To achieve this aim, the study's methodology was informed by social constructionist grounded theory [30, 33], as grounded theory methods aim to produce an understanding of a social phenomenon which is led by the data, grounded in the accounts of those experiencing it, and, therefore, resonates with their experience and makes sense to them [34-36]. Although the original formulation of grounded theory, the "discovery of theory from data" [34], has been criticised (including by feminist scholars [37]) for remaining within a positivist paradigm, Charmaz aimed to develop a grounded theory method better suited to the interpretivist paradigm, and a social constructionist theoretical position. I therefore utilised the "systematic, yet flexible, guidelines" [33] offered by this method, which enabled a close and in-depth analysis of the data. Key feminist methodological and ethical principles were also integral to the research methodology. Feminist research aims to develop knowledge which is reflective of women's own voices [38, 39], and positions women's subjective meanings as central to understanding their experiences. It also seeks to understand the influence of social structure and culture on women's experiences and perceptions. Feminism and social constructionist grounded theory are complementary as both approaches position participants as central to the research, and their experiences as a legitimate source of knowledge [40]. It has also been argued that grounded theorists can learn much from feminist practices of reflexivity [37].



## *Research design*

Participants were accessed through a diverse group of gatekeeper organisations and support groups.

The inclusion criteria for the study, developed from the literature review, were:

- Woman diagnosed with breast cancer while aged between 18-44
- Diagnosed at least twelve months previously, and within the last ten years
- Completed initial treatment in the UK
- Not currently receiving treatment for cancer, other than long-term preventative treatment such as Tamoxifen

The age range was chosen because the age of 44 is well below 50, which is the age over which the majority (80%) of breast cancers are diagnosed. It is also well below the average age (50-51) of menopause, increasing the likelihood of reaching a group of women who were pre-menopausal at diagnosis, an issue which the literature review indicated was significant. Twenty women took part in qualitative, semi-structured interviews, and a further three women who met the inclusion criteria participated in three stakeholder panel meetings throughout the course of the research, in order to engage women in the research. Semi-structured interviews gave women a level of freedom to choose how to tell their stories, consistent with feminist research methods, but also enabled me to provide prompts and to further investigate areas identified as important through the literature review and preliminary analysis, consistent with grounded theory methods.

The data analysis was informed by Charmaz's (2006) guidelines for grounded theory methods of analysis, and involved three phases of coding data. Coding refers to "categorising segments of data with a short name that simultaneously summarises and accounts for each piece of data" [33].

Preliminary analysis in the form of initial coding was conducted concurrently with data collection.

Initial coding was conducted with the aim of summarising each segment in terms of processes, rather than applying pre-existing theoretical categories to it. Some segments were coded in the women's own words which enabled their understandings and perceptions to remain intact. After the initial

phase, I conducted focused coding. This involved sorting and synthesising initial codes, and making decisions about which codes were the most useful, significant, and effective, in building an interpretation of the data. Finally, I focused the analysis by drawing on each element of the theoretical framework in turn, in order to explore in depth the women's accounts in relation to each research question.

Reflexivity, a critical reflection upon how the position, background, knowledge of the researcher shaped the research, is regarded by many as an essential aspect of qualitative research [41], especially feminist research [38, 39, 42]. Given that a feminist methodology positions women's knowledge as arising from their subjective experience, the researcher must also be viewed in the same way. There were undoubtedly ways that my social position as a white, able-bodied, heterosexual, young woman studying at a university, shaped how I was perceived by participants, and the conversation in the interviews. An important difference between myself and the interviewees was that I had not had breast cancer, and this inevitably impacted on the interviews. For example, some women may have wanted to protect me from the most distressing parts of their story. On the other hand, many women used the opportunity to confide in me their fears and other distressing emotions. As a young woman myself, I became acutely aware that the women's stories were also potentially my story. I remember sensing this particularly when interviewing Naomi because when Naomi was diagnosed, she was the same age as I was at the time of the interview, a fact of which we were both aware during the interview, as she had asked me my age before we began.

Ethical considerations were crucial when designing the study, and the research was approved by the Humanities and Social Sciences Research Ethics Committee at the University of Warwick.

Researching sensitive subjects such as the experience of a serious illness and its effects on a woman's perceptions of her body and identity, raises the potential for causing distress, and the interviews were carried out with the greatest care to remain sensitive and respectful towards the interviewees. Consent was understood as a process [43] negotiated throughout the research, with participants being informed that they were not obliged to take part, nor answer every question, and reminded that they could

withdraw at any point, including after the interview. Throughout the interviews, I made sure women understood that they were under no obligation to answer any questions, or speak about any topics which they felt were too private or which they did not feel comfortable speaking about. I also spoke with them about the aim and purpose of the research, and informed them about how their accounts would be treated. I made sure that they felt comfortable with their voice being recorded and transcribed, and assigned them a pseudonym, removing any potentially identifiable information.

### *The interviewees*

The young women who took part in the study ranged in age from 26 to 53, and were aged 22-43 at diagnosis. The time since diagnosis ranged from 15 months to nine years, with an average of 3.5 years. Table 1 provides more demographic and treatment information about the participants. Most of the women (17) were married, civil partnered, or cohabiting, two were in relationships and one was single. Three women interviewed were pregnant when they were diagnosed, all with their first, and at the time of the interview, only, child. All women had completed their initial treatment, receiving a combination of the most common forms of breast cancer treatment: surgery, chemotherapy, and radiotherapy. All women were interviewed after their first diagnosis of breast cancer, with the exception of one woman, who had been treated twice after it was discovered to have spread one year after her first diagnosis. Nineteen of the women received long-term preventative treatment such as Tamoxifen, Zoladex, or Herceptin. Fifteen women received chemotherapy, and nineteen underwent radiotherapy.

<u>Characteristic</u>	<u>Number (Percentage of sample)</u>	<u>Range (Mean)</u>
<b>Age at diagnosis</b>		22-44 (33.8)
<b>18-24</b>	1 (5)	
<b>26-30</b>	6 (30)	
<b>31-35</b>	4 (20)	
<b>36-40</b>	4 (20)	
<b>41-44</b>	5 (25)	
<b>Age at interview</b>	-	26-53 (37)

<b>Time since diagnosis</b>	-	15 months–9 years (3.5 years)
<b>Ethnicity</b>		
<b>White</b>	17 (85)	
<b>Asian</b>	1 (5)	
<b>Black</b>	1 (5)	
<b>Dual heritage</b>	1 (5)	
<b>Sexual identity</b>		
<b>Undisclosed</b>	18 (90)	
<b>Lesbian</b>	2 (10)	
<b>Disability (before diagnosis)</b>		
<b>None</b>	18 (90)	
<b>Yes</b>	2 (10)	

## Findings

Uncertainty emerged as a significant theme in the women's accounts of their lives after treatment. The young women faced uncertainty about two areas: the possibility of recurrence and their status as survivors; and fertility and the future of their life course. The young women's assumptions about their lives were challenged during the diagnosis and initial treatment stage, but the implications for the rest of their lives were as yet uncertain, and this was something which the women described as having to face from the end of curative treatment.

### *Uncertainty about recurrence and cancer-free status*

The young women experienced profound uncertainty surrounding the question of whether their treatment had been successful, and whether they would experience a cancer recurrence. The treatment ended, it seemed, abruptly, and women had expected to feel positive and well, especially at the end of chemotherapy. Instead, they found that they felt emotionally and existentially vulnerable, reflecting on the enormity of the experience of having gone through cancer treatment and its implications for their future. The fear of recurrence has been noted in other studies about the experience of breast

cancer from the perspectives of women of all ages [44-46]. The young women in this study felt that it was particularly difficult for them to face their mortality and the possibility of a foreshortened life span at their age. They considered the risk of recurrence and its implications for them as younger women.

‘If you get cancer when you’re 60 and you look at it that you may get it in ten years’ time you’re at a fairly good age, whereas if I get it back when I’m 40, which might not happen but there’s still a huge chance that it will, I’m still like super young really at 40.’ – Lyndsey, 31 at diagnosis

‘Because I was like 22 when I was diagnosed I think, y’know, “What’s a nice age to live to? I guess like 82” and I kind of always said to myself “Am I really gonna go sixty years without getting cancer again?”’ – Faith, 22 at diagnosis

These accounts demonstrate poignantly the significance of age to young women’s lives after breast cancer, and having to live for such a long time with the burden of this uncertainty.

The women felt heavily reliant on medical knowledge to define them as being healthy or ill, as having cancer or not, yet, after the end of initial treatment, the young women were confronted with the realisation that medical knowledge was limited in its ability to define them as cancer-free.

‘No one scans you and says “You’re alright now”, they just say “We think the treatment we’ve given you should kill any cells that are possibly stray”.’ – Lyndsey, 31 at diagnosis

“It’s not spread as far as I know, at the moment they say it’s nothing – ‘No evidence detected’ they say at the minute.” – Beverley, 36 at diagnosis

As a result, the young women found that they could not perceive themselves as cancer-free. The language many of them used showed that they perceived cancer to be lurking within their bodies.

‘For all I know my cancer could still be there, like a tiny little cell that one day will explode.’  
– Melanie, 27 at diagnosis

‘There’s an element in my head of worrying if it’s still there lurking.’ – Dawn, 27 at diagnosis

Exacerbating this, was the sense that others around them assumed that they were now ‘well’, but this was contrary to how they felt.

‘Everybody thinks I’m back to normal it’s kind of like “Oh you’re fine now, you beat it”. I haven’t beat it I’m still, not even in remission they don’t even call it that it’s kind of like I’m still trying to prevent it from coming back...And you kind of want to shake people and go “I’m not okay, just listen to me!”’ – Gemma, 33 at diagnosis

Gemma’s account is indicative of Little *et al.*’s (1998) theme of ‘cancer patientness’. The young women could not easily see themselves as cancer-free, and cancer was experienced and perceived as an ongoing presence in their thoughts, and even in their bodies. Rather than being categorised as either ill or well, the young women found themselves in a space ‘betwixt and between’ healthy and ill [47]. Participants also described hiding their ongoing fears about recurrence from people around them, and feeling unable to express the reality of their experience to others because of the assumption that they were now returned to normal. This can be understood as ‘communicative alienation’ (Little *et al.* 1998), a facet of being in a liminal state.

#### *Uncertainty about fertility*

A further dimension of uncertainty which the young women experienced was surrounding fertility and menopausal status, and this was a significant theme in many of the interviews. The impact of breast cancer treatment on an individual woman's fertility is difficult for health professionals to determine. Reproduction and fertility have been identified in previous studies as among the most important concerns of younger women living with a history of breast cancer [20, 44, 46], but here I highlight the importance of the *uncertainty* about fertility and the way that this can be understood as a liminal state for the young women.

Thirteen of the participants told me that at the time of their diagnoses either that they had been planning on having (more) children, or that they were undecided but had not ruled it out. Many of the women interviewed were therefore hoping that the menopausal symptoms they were experiencing were temporary, their menstrual cycle would return to normal once they finished hormonal treatment, and that they would then be able to conceive.

‘I’ll find out in the next few years whether I can [have children] or not, assuming I’m in the position to start.’ – Faith, 22 at diagnosis

Even those women who were no longer receiving long-term hormonal treatment, and had been told by their doctors that their fertility was normal, were still experiencing profound uncertainty.

‘I asked my oncologist to give me a fertility test and he’s like ‘Yep you’re fertile’. But I know I will never know until I, fingers crossed, try to have children.’ – Melanie, 27 at diagnosis

For Naomi, becoming pregnant was a major goal and would be the point at which she would feel recovered from the cancer.

‘We’ve got two years left of Tamoxifen...And then we’ll start trying for a baby. Which is the ultimate goal now, after, and that will be my “That’s it, put it behind me”. That’s always been like my end to it all. So I’ll be living it now until that moment where I can say “I’m pregnant”. And then I’m gonna put it behind me as much as I can.’ – Naomi, 26 at diagnosis

The uncertainty which arose with regards to fertility can be understood as a suspended state in which the women were unable to categorise themselves as either fertile or not, able to have children or not, and many of the young women were waiting to not only move on to the next phase of their lives, but waiting to see what would be possible within the next phase.

All but four of the women were still on long-term hormonal treatment at the time of interview, such as Tamoxifen, which inhibits the amount of oestrogen absorbed by cells in the body in order to prevent recurrence. The length of this preventative treatment, and therefore the length of their treatment-induced menopause, was largely unclear for the young women, adding yet another layer of uncertainty.

‘[It would] just be nice if they say after five years: “That’s it we can stop it”.’ – Gemma, 33 at diagnosis

Some of the participants were told when they began treatment that they would be able to come off Tamoxifen after two or three years in order to have a child and then go back on it to complete the five-year recommended course. However, this was something which the women were unsure would actually happen.

‘I need to be on it [hormone treatment] for minimum five in total but he has said that after two years I can maybe have a break to have a child.’ – Hayley, 29 at diagnosis



‘After three years of taking it, if it’s all clear and we’re happy, we could think about coming off it to try and have children... We just have to see how it goes.’ – Evelyn, 33 at diagnosis

It seemed that, for some women, if they did not experience a recurrence within the first two or three years they might be able to take a break from their hormonal treatment in order to have children.

Uncertainty about recurrence and fertility were, therefore, interlinked. Little *et al.* (1998) argued that their participants continued to speak from the position of ‘cancer patient’, regardless of the time since their treatment. It is clear that although the women in this study did not have cancer, and were not cancer ‘patients’, neither did they feel that they had fully moved on to being ‘well’. A few of the women had tried to negotiate taking this break from their Tamoxifen regime in order to conceive. However, this was less straightforward than they had hoped, and they had found their doctors resistant to the idea.

‘I went in and I said ‘I want to finish’ and he said “No”. I said “I’d like to start having kids” and...He looked at me and said “Naomi if you stop your Tamoxifen now and have a baby you won’t be here to look after it”.’ – Naomi, 26 at diagnosis

Diagnosed at the age of 26, Naomi expressed her sense of injustice at, and frustration with, this loss of control. She described the above exchange as ‘Like a 60-year-old man is controlling my life’. With their life course disrupted and constrained by the treatment timescale, the young women had to balance their wishes to have children, with the importance of preventing recurrence.

‘I just can’t wait until it’s over, I just can’t wait. It’s like a pause on my life.’ – Naomi, 26 at diagnosis

This highlights important distinctive aspects of young women’s experiences of living with a history of breast cancer: that of uncertainty regarding fertility; the length of time of such uncertainty; and the implications of breast cancer on their life course. Waiting until the end of long-term treatment, or until

their oncologists agreed that they could take a break, to find out if they could conceive, was experienced as a liminal state. Uncertainties and fears about recurrence and fertility therefore interweaved to produce an uncertain future for the young women.

The treatment for breast cancer for a young woman, can last over six years when surgery, chemotherapy, radiotherapy, and hormonal preventative treatment are taken into account. This had particular implications for the some of the young women who were at a certain stage in their life, as it meant that the following six years from diagnosis would be dramatically different to the way the women had planned or anticipated them to be, displacing their major life plans.

‘My Mum had an early menopause at 40, 41, and I knew...I would have to have Tamoxifen for five years and that I wasn’t allowed to get pregnant in that space of time...I knew then that I’d be 38, 39 coming out of it and that I’d have only a tiny little window, potentially a tiny window to get pregnant.’ – Evelyn, 33 at diagnosis

Evelyn’s account illustrates the importance of timing. For Evelyn, the years on Tamoxifen stretched out ahead of her, and the time between the end of treatment and her anticipated early menopause was too short, restricting her chances of having children. The end of hormonal treatment does not immediately signify the point at which women might be able to conceive; the drug takes time to leave a woman’s system, and women are advised not to try to become pregnant for twelve weeks (Hickey *et al.* 2009).

Like participants in another study [48], the women often held perceptions about the ideal time to have children, and breast cancer treatment left this temporal trajectory in disarray.

‘I was kind of hoping that I’d have a child by at least 35, one, um, and we want to have a couple, so at least by the time I was 40 I was thinking we’d have two children. Um, and that’s just not gonna happen now.’ – Evelyn, 33 at diagnosis

Many of the young women felt that they were deviating from a 'normal' life course, as well as their personal anticipated life trajectory, often comparing themselves to other women their age.

'All my friends and everyone around me is on one path and I'm kind of going, poodling on another.' – Naomi, 26 at diagnosis

Naomi's use of 'poodling' indicates that she viewed the time on Tamoxifen to some extent to be wasted time, illustrating her experience and perception of a suspended state. Melanie described the sense of urgency which she felt to meet a partner and complete certain goals before she experienced a recurrence:

'Yeah deep down I think to myself "God I need to meet someone quickly and have them fall in love with me" because God forbid it comes back.' – Melanie, 27 at diagnosis

Existing research has noted that women with breast cancer experience a loss of control over their bodies and lives (Dunn and Steginga 2000; Thomas-MacLean 2004; Trusson 2013). Halliday *et al.* (2014) also found that loss of control was a strong theme in their study about the experiences of women who were uncertain about their fertility after haematological cancer treatment. In Little *et al.*'s conceptualisation of liminality, a theme was 'boundedness'. The findings here highlight that young women with breast cancer experienced a loss of control which was related to their age at diagnosis and the implications of treatment for their life course. The women in the present study felt a loss of agency over their lives, bound by new rules of time.

Not all of the young women were hoping to become mothers, and some of them had already had all the children they were planning to. Seven of the women were not, at the point of diagnosis, planning on having any (more) children. It is important not to neglect these women's accounts, or to imply that all young women wish to have children. However, concerns about menopause and fertility did not necessarily relate to a desire for children, and an uncertain menopausal status had an impact on

women's identities regardless of whether they wanted children. None of the women interviewed had experienced menopausal symptoms before their treatment.

For the women who were not planning on having children after treatment ended, uncertainty and liminality still characterised their experiences because they were unsure if they would return to a pre-menopausal state after treatment.

‘Once the injections are finished they don’t know whether my periods will restart, they can’t tell me that.’ – Beverley

Some of the women were hoping their periods would resume and their menopausal symptoms would subside until they became naturally menopausal later in life. Others were hoping that the treatment-induced menopause was permanent.

‘They’re testing me at the moment just to see if I’ve actually gone into full menopause, um which I don’t mind if I have, but it would answer a lot of questions...I would stop worrying about it so much “Oh is it the drugs and if I stop taking them will all these things suddenly come back with a vengeance?”.’ – Sarah, 41 at diagnosis

This builds on previous work on liminality, providing evidence that the young women found themselves between two positions: neither menopausal nor pre-menopausal.

### *A new normal?*

It could be argued that some women find it useful to frame their lives living with the uncertainty engendered by cancer as ‘normality’, as Trusson did. People with a history of cancer know that they are unlikely to ‘return’ to a previous normality, so they need to construct a new normal. Indeed, one woman in my study used the term ‘new normal’ unprompted:

‘It’s normal for me to wake up feeling about 80, like if I got up now I would probably hobble for a little bit but be fine and it’s just a new normal for me.’ – Beverley, 36 at diagnosis

However, I think most of the accounts of the young women in this study raised a question about how relevant this concept is to understanding their experiences and perceptions. The uncertainties which arose from their experience of cancer, and the constraints placed on their lives as a result of the treatment, suggest that the women were in a state of liminality, waiting to find out what the implications for their lives would be, and if cancer would return before they were able to reach their life goals.

‘At work sometimes I do walk along my corridor if I’ve had a good day and I just think “This is great I’m okay”, and I do have that fear, I definitely do, that I need to hurry up with things, I want to sort out my life like just in case I get ill again.’ – Melanie, 27 at diagnosis

While authors [14, 26, 27, 49, 50] have conceptualised this liminal state as the new normal, it could be argued that labelling it as normality obscures young women’s perception of their current state as temporary. For example, one study explores how women adapt to a new normal by rebuilding their identity through breast reconstruction [27]. However, for a young woman unsure of her menopausal and fertility status, being able to rebuild her identity on any solid ground is precluded by the temporary nature of her situation. The ambivalence which women expressed in their interviews illustrated that, while there were positive outcomes of breast cancer and their lives had, in many ways, resumed previous routines and structure, the sense that their current state was only temporary was ever-present, and uncertainty and liminality permeated their everyday lives.

## **Discussion**

The accounts of the young women above suggest that the end of initial treatment was accompanied by a sense of unease and uncertainty in relation to recurrence and survival, and fertility and menopausal

status. These experiences resulted in a liminal state (Little *et al.* 1998). The young women found this experience of profound uncertainty at the end of initial treatment to be in contrast to their own and others' expectations of life after cancer. It has been argued elsewhere that there is an emphasis on a return to 'normal' after cancer treatment (Little *et al.* 1998), but that this does not reflect the reality. The women in this study found themselves feeling distant from others because they could not communicate the uncertainty engendered by living with a history of cancer. This can be understood as 'communicative alienation' which Little *et al.* identified as a facet of liminality.

As in Little *et al.*'s formulation of liminality, the young women experienced a sense of being bound by time in ways which they had not been before. The young women's perceptions about the future were altered, and their fears about recurrence were magnified by the possibility of so many decades ahead during which breast cancer could recur. The constraints of treatment timescales meant that, after initial treatment, young women with a history of breast cancer experienced a loss of control or agency over their life course, as their futures would be determined by the recommendations of health professionals, and whether or not they experienced a recurrence while on Tamoxifen. The implications for the young women's life course, in terms of whether they would be able to have children, would not become clear for several years after initial treatment. Even the women who were told that their fertility was normal remained unconvinced and uncertain.

Regardless of future family plans, the uncertain menopausal state which treatment induced for many of the young women was experienced as a liminal state because of the inability of health professionals to define their menopause as permanent or temporary. As a result, they found themselves situated "betwixt and between" fixed identities (Hockey and James 2003:24): neither clearly post- nor pre-menopausal. Most of the young women would have to live with an unknown fertility, and an unknown menopausal status, for many years after initial treatment. While previous research (Trusson 2013) has identified liminality in the accounts of women with a history of breast cancer, this dimension is related to the young's women's life stage at diagnosis, and it therefore extends understanding of life after breast cancer. This dimension of uncertainty is central to understanding

young women's experiences after breast cancer. Previous researchers have identified the significance of uncertainty regarding fertility for women living beyond cancer, and called for further research into this issue (Halliday and Boughton 2011; Halliday *et al.* 2014; Perz *et al.* 2014). This paper has aimed to increase understanding of uncertainty after breast cancer. It has also emphasised the importance of timing and time in understanding the experience of living beyond breast cancer.

### *Strengths and limitations of the research*

The decision to use semi-structured interviews enabled a shared control over the interview, to some extent, and also the flexibility to explore emergent issues. Data from interviews should be seen as a product of a given social interaction, rather than a straightforward, objective account of 'the truth' [51]. However, the aim of the study was to explore the young women's own perspectives on their experience, and, therefore, interviews enabled this. Little *et al.* (1998) argued that liminality after cancer was an enduring state, one which may continue until the end of a person's life, whether from cancer or another reason. Further research could explore this in the accounts of young women living ten or more years beyond breast cancer.

### **Conclusions**

These findings contribute to a nuanced understanding of the impact on young women's life course after breast cancer, identifying ongoing uncertainty as central, and identifying age-related dimensions of liminality. The young women's horizons had shifted in the same way that they might for older women, but the long-term consequences for their life course would not become clear for many years after diagnosis, and uncertainty about survivorship, and their futures, permeated their everyday lives. Reproduction and fertility have been identified in previous studies as among the most important concerns of younger women living with a history of breast cancer [20, 44, 46], but here I highlight the importance of the *uncertainty* about fertility and the way that this can be understood as a liminal state for the young women.

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